



Queensland University of Technology
Brisbane Australia

This is the author's version of a work that was submitted/accepted for publication in the following source:

[Stafford, Lisa](#)

(2014)

The Journey of Becoming Involved in Urban Spaces by Children with Diverse Mobility.

In Buccieri, Kristy (Ed.) *Body Tensions: Beyond Corporeality in Time and Space*.

Inter-Disciplinary Press, Oxford, United Kingdom, pp. 97-120.

This file was downloaded from: <http://eprints.qut.edu.au/76201/>

© Copyright 2014 Inter-Disciplinary Press

No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means without the prior permission on Inter-Disciplinary Press.

Notice: *Changes introduced as a result of publishing processes such as copy-editing and formatting may not be reflected in this document. For a definitive version of this work, please refer to the published source:*

<http://www.inter-disciplinary.net/publishing/product/body-tensions-beyond-corporeality-in-time-and-space/>

Author's version:

This version of this article originally appeared in:

Stafford, L. 2014. "Journey of Becoming Involved in Urban Spaces by Children with Diverse Mobility". In *Body Tensions: Beyond Corporeality in Time and Space*, edited by K. Buccieri, 97-120. Oxford: Interdisciplinary net.

The Journey of Becoming Involved in Urban Spaces by Children with Diverse Mobility

Lisa Stafford

Abstract

Participation is a word frequently espoused in the literature of childhood and urban studies. It has also been made sacrosanct through the Convention on the Rights of the Child and other rights-based policy and programming. Despite this importance, what it means and how it is experienced in the everyday lives of children with diverse abilities is not well understood. This chapter provides insight into the everyday experiences of participation by ten children 9-12 years of age, who have diverse personal mobility from various physical conditions that affect muscle and movement differently, including: Muscular Dystrophy, Cerebral Palsy, and Autoimmune Rheumatic Diseases. The children participants live in the outer suburbs and inner regions of south-east Queensland, Australia. The chapter discusses a new way of understanding and theorising participation as a *journey of becoming involved*. This knowledge emerged through the children's body-space-time routines (body ballets) and their descriptions of inhabiting urban space. This chapter also establishes how body-space-context interplays shape the experiences of becoming and being involved in everyday life, as well as the preconceptions of body embed in space which divide and constrain children and families actualisation of full and genuine participation.¹

Key Words: Children, body, mobility, physical disability, children's participation, urban spaces, embodiment, interpretive phenomenology.

1. Introduction

The study of children's participation is an expanding field of study. One key future direction of the field is to build on its understanding and theorising of

children's participation to better encapsulate the complex interface between socio-cultural, legal-political, and spatial-temporal aspects of society that challenge children's opportunities to attaining full participation. Another key area of development is addressing the limited recognition and understanding of children's participation, as it pertains to the diversity of children and their circumstances. An important starting point in this development is the acknowledgment that some children and young people's opportunity and choice of participation is tightly prescribed through social, physical, and cultural structures.² An illustration of this experience is found in other chapters of this volume as well, such as in the body tensions encountered by young people experiencing homelessness in Kristy Buccieri's chapter.³ Scholars, such as Egilson and Traustadóttir, have examined diversity and 'children's participation' as it pertains to children with disabilities in the school context.⁴ Their study raised specific concerns with homogenisation of both *children* and *childhood* in theorising participation, and has highlighted the need for further understanding and theorising, particularly in regards to the interface between childhood and disability.⁵

This chapter helps add to this development of knowledge in childhood and disability by presenting a different way of understanding participation, as a *journey of becoming involved*. It is emergent from the accounts of children, aged 9-12 years, who have diverse personal mobility due to physical conditions such as Muscular Dystrophy, Cerebral Palsy, and Autoimmune Rheumatic Diseases. The children's diversity in mobility, both in body movement and in the occupying of space, provided the opportunity to explore and understand participation from a range of children who are commonly bundled together under the label *physical disability*. In addition, it sought to understand children's own meaning and sense-making of participation, through the children's body-world relationship and how it played out in everyday life as time-space-body routines.

This chapter will spend the majority of the time describing the complex and layered structure of meaning of participation revealed and understood by the children in this study. However, to aid this journey, the chapter will begin by establishing the linkages between children, corporeality, and participation. The chapter will then outline the theoretical lens applied to understanding *children's participation*, followed by a summary of the research design applied to capture the complex and multiple interactions that occur between children and the urban spaces in their lives. This then leads to the poignant accounts of becoming-involved in urban spaces by the children, revealing differences in the way spaces were experienced and the (re)production of these differences through the interplay between body-space-context.

2. Linkages between Children, Corporeality, and Participation

Despite *children's participation* being a concept located throughout childhood and urban studies, as well as social and urban policy, little attention has been given

to the diversity of children and childhoods. Children with disabilities are one such group of children who have been given little recognition, despite frequently experiencing difficulties in achieving full participation in their education, health, housing, leisure, and in being seen, heard, and taken seriously.⁶ Reasons for this are twofold: (i) definitional inconsistencies; and (ii) bodily assumptions.

Firstly, the definition of what participation actually means is not agreed upon in the discourse of children's participation; there is divergence in what children's participation is believed to be and how it is studied and practiced. This is summarised by Williams and Invernizzi: 'despite growing interest and publications over recent years, children's participation remains, however, difficult to conceptualise.'⁷ Different definitions coexist and there is no clear and holistic theoretical framework. This issue is amplified when reviewing literature on participation as it pertains to children with disabilities. For example, the health field predominately focuses on function and performance, whereas the childhood field focuses on everyday environments and culture. Scholars have indicated much more understanding is needed, particularly regarding the diversity of children and their everyday experiences.

Secondly, children's opportunities to experience full participation are linked to assumptions of competency, which researchers contend are associated with the perception of the human body. Specifically, James believes children's access and agency within the urban environment is controlled by others based on bodily assumptions about children's competencies.⁸ James has identified five features of the body as gauges informing judgement, these are: 'height, shape, appearance, gender, and performance.'⁹ Children who speak, move, and occupy space differently than the *normal* perceived body are constantly being judged, which in turn has implications for their involvement in many realms.

The discourse of disability across existing studies on the topic has discussed how negative perceptions of capacity and capability arise from bodily assumptions perpetuating the exclusion of children with disabilities, even in environments deemed 'child' or 'accessible' friendly.¹⁰ Scholars suggested that this is because children with disabilities are perceived as *other* than a child, according to their bodily differences. Being deemed *other* based on body, according to Jones and Bassar-Marks, means being 'inhibited from full participation in society'.¹¹ This means for children with disabilities that the opportunity for, and extent of, their participation is restricted in many aspects crucial to everyday life.

This link between body and participation has been explored by scholars in feminism, and disability researchers have studied the relationship between the body and socio-spatial oppression in everyday spaces. For example, Young's phenomenology of the female body describes female oppression that arises through the body:

Insofar as we learn to live out our existence in accordance with the definition that patriarchal culture assigns to us, we are physically inhibited, confined, positioned and objectified. As lived bodies we are not open and unambiguous transcendences which move out to master a world that belongs to us, a world constituted by our own intention and projections.¹²

Likewise, in disability geography, researchers have asserted that one reason for persons with disabilities' exclusion from environments in everyday life stems from negative perceptions towards the diverse body. Respective studies by Scully, Morris, and Toombs reveal how one's value and recognition is tied to the corporeal form, illustrating how the *normal* body (upright, forward-facing adult) is assigned value and autonomy, whereas bodies that vary from this norm lose autonomy and value.¹³ This lack of assigned value and autonomy towards people with diverse bodies often results in socio-spatial oppression.

Given the importance participation has to one's humanness and everyday life, and that children with disabilities are frequently denied their rights to full participation because of complex layered assumptions, the study problematised participation as it currently existed, and instead developed an understanding of it as a phenomenon of human experience. To specifically address the diversity of children's bodies and their world relations, children with diverse mobility were selected, and understanding was concentrated through the body as an 'experiencing agent.'¹⁴ The theoretical and methodological approach applied to understand children's participation will now be outlined.

3. Theoretical Approach to Understanding Children's Participation

With the emergence of the interactional model of disability, concepts of the *body* and *embodiment* have re-emerged as important in understanding disability and emancipation. Hughes and Patterson contributed to this shift through viewing the body as a 'site of meaning and source of knowledge about the world' that aids understanding of a person's embodiment.¹⁵ Shakespeare also contributed to this emergent field through a focus '...on the interaction between the people, the environment and the context,' which he contended is the 'key to improving the participation experience of people living with impairment.'¹⁶ In acknowledging these two views, the study brought together three different but related theoretical-philosophical positions that form the framework to understanding participation as a phenomenon of human experience.

The foundational work of Lewin's study on person and the environment provided an overarching framework for understanding experience in a holistic and integrative way.¹⁷ According to Lewin's work on behaviour and development, experience is a function of the total situation. His formula, ' $B = f(P, E)$,' captures that the behaviour or action of an individual is the function (f) of the person (p),

their perceived environment (e), and the interaction between the two.¹⁸ Emerging from Lewin and his students' studies of person-environment relationships is Field Theory, which considers external environmental factors, including the spatial aspect and its relationship specific to the person in that specific context.¹⁹ Lewin's Field Theory asserts that 'a person's behaviour is best comprehended by the structure and dynamics of the field.'²⁰ Generally field theory seeks to describe 'the present situation known as the field,' in which the person participates.²¹ This approach helps to understand the total situation which shapes children's experiences in the urban world, as well as explicating reasons of differences and paradoxes experienced by children with diverse mobility. However, the approach alone does not provide a focus to grasp the felt meanings and experiences of participation, as understood by the children. The intimate theoretical positions of existential phenomenology and geographical phenomenology provide means by which to grasp this understanding.

Enabling greater scrutiny of the person as body is Merleau-Ponty's concept of the habitual body (body-subject): 'I am conscious of my body via the world and I am conscious of the world through the medium of my body.'²² According to Merleau-Ponty our point of reference in the world is through our Corporeal Schema (Body-Subject), which guides our body's movement unthinkingly. Conflict encountered between one's Habitual Body and the Body-in-Moment can immobilise motility and profoundly disturb one's reference in the world, when the body cannot adjust unthinkingly. This applied understanding of the body guides how experiencing agents interpret and negotiate interaction, meaning, and movement in everyday life.

How children live with their world is understood from the perspective of geographical phenomenology. Seamon's typology of habitual movements of everyday life helps to reveal our sense of place in the world. The first level of the typology is the *body ballet* which is described as a 'set of integrated gestures, behaviours, and actions that sustain a particular task or aim, for example, preparing a meal, driving a car, doing home repair, and so forth.'²³ When the body ballet occurs around a particular act and set time it becomes known as a *time-space-routine* - the second level of the typology. The third level of the typology, *place ballet*, is said to produce a sense of existential insideness through regularity, continuity, and repeated meeting with people who share in the activity in the space. Seamon believes that '...body, habit and space transformed into place' give rise to place choreographies.²⁴ This typology helped focus the orientation to children's descriptions of their habitual routines in their everyday world, and the layers of habitual routine offered a means of exploring and interpreting children's experiences of participation.

The concept of sense of place is further understood through Relph's model of insideness / outsideness.²⁵ Relph described how one's identity of place consists of three components: 'place as physical setting; place as an activity, situation or

events; and place as an individual or group meaning.²⁶ One's identity *with* place, however, provides understanding to the lived intensity of experience. The terms *insideness* and *outsideness* were used by Relph as a descriptive language of a person's identity with a place. Seven modes of insideness /outsideness were identified by Relph, each being a different 'level of experiential involvement and meaning.'²⁷ Insideness describes one's degree of felt attachment to, and involvement with, a particular place. A vastly different feeling related to place is a felt sense of outsideness - a sense, which can be felt through remoteness, vulnerability, inhospitality of situation or, being out-of-place.

In conjunction with the concepts of *habitual routines* and *sense of place*, Lang's concept of *inhabiting* helped to reveal intentionality to transform space to place by children and their families, through the act of incorporation.²⁸ Intentionality 'is a basic structure of human existence that captures the fact that human beings are fundamentally related to the contexts in which they live.'²⁹ From Lang's work, inhabiting is exemplified as an important part of human existence and the sense of being in the world. Combined, these concepts provided geographical perspective to participation that recognises the distinct person-environment relationships expressed through feelings, acts, and experience, as well as elements of landscape, space, and place. This perspective provided a fresh position from which to understand participation from the geographical experiences of children with diverse mobility (refer to Image 1).

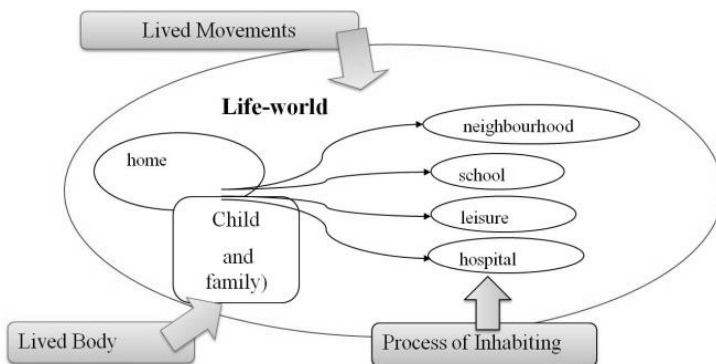


Image 1: The Applied Phenomenological Lenses.
Image Courtesy of Lisa Stafford

4. Method

Three research questions framed the approach and analysis: (i) what are the different ways children experience participation in urban spaces; (ii) how are these differences in participation (re)produced through body-space interactions; and (iii)

why do children with disabilities experience what they do? To answer these questions, by uncovering their implicit meaning and experiences, required the application of the abductive research strategy from the interpretive paradigm. Abduction is the study of the 'everyday' of people's lives to reveal the 'full meanings and interpretations produced by social actors to explain their reactions, other people's actions, social situations, and natural and humanly centred objects.'³⁰ Its ontological assumption is that *social reality* is the 'product of processes by which social actors together negotiate the meanings for actions and situation.'³¹ Epistemologically, knowledge is understood to embed in the everyday life. In order to the grasp this knowledge, researchers need to enter inside the individual's everyday experiences.

Building this knowledge was a staged process; the *first stage* of abduction is to provide a descriptive level account of the phenomenon from the first-order descriptions of social actors. Applied to this study, this involved developing a descriptive account of children's felt experiences of participation in their urban world. This descriptive level account is described and interpreted from an Interpretive Phenomenology focus with a lifeworld orientation.³² The *second stage* of the abduction strategy is to transform the first-order descriptions to second-order descriptions by locating categories and concepts that can explain the first-order felt experiences. This was achieved through Charmaz's Grounded Theory methods.³³ Both methodologies, Interpretive Phenomenological Lifeworld and Grounded Theory, were adopted to reveal the implicit meaning of children's participation from everyday experiences in their world. Together they provided the capacity to capture the complexity, differences, and multiple interactions of body-space-context that are experienced in the urban world and, in doing so, help generate new knowledge.

Participants, as mentioned earlier, were purposefully sampled to reflect the diversity in body and mobility that exists within the label *physical disability*, in order to explore experiences of participation. Non-government organisations provided access and in-kind support with recruitment. The diversity of the children and their needs informed the design and delivery of the data generation, specifically the need to: accommodate the range of physical needs, be sensitive to the physical and emotional comfort of participants, and accommodate the many ways in which children express their voice.

A pre-interview meeting was undertaken to gather consent, build rapport, and identify any specific needs of each child in order to further adapt the methods.³⁴ Data generation occurred over three visits in 2010 and 2011, within the children's homes, and each was designed and implemented as an activity-based interview.³⁵

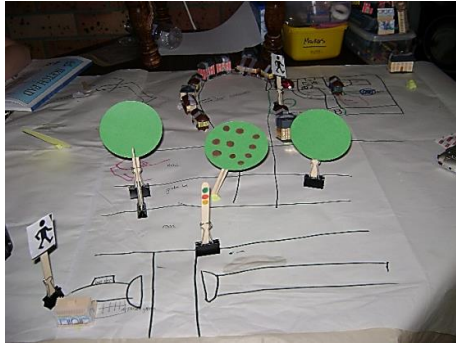


Image 2: Example of a Mapping Activity used as to Generate Data.

Image Courtesy of Lisa Stafford

As shown in Image 2, these activities were designed to elicit meaning and felt experience, as understood by the participants. The semi-structured interviews occurred throughout each activity and were built upon over the course of the research.

Data analysis was undertaken using Charmaz's Grounded Theory coding process³⁶ and Interpretive Phenomenological Lifeworld approach³⁷ to identify themes, meaning and interconnections emergent from the narratives in the data. The final aim of the analysis was to reveal the essential phenomenological experience of participation, which was understood as a journey of becoming involved. The essential qualities of the *journey* will now be described.

5. Journey of Becoming Involved

The conceptual framework of this study contends that children's bodies are their perceptual frame of the world. Specifically, each child's way of inhabiting the world 'gives meaning to how things are apparent to oneself,' and is their perceptual frame which provides familiarity, autonomy, and sense of self in relation to the world.³⁸ Out of the ten children selected, there were five different perceptual ways of moving and occupying space in their world. These included two children walking unaided, two children walking but tired over distances, one child walking with crutches, four children moving by self-driving power wheelchairs, and one child moving by manual wheelchair pushed by others (refer to Image 3).

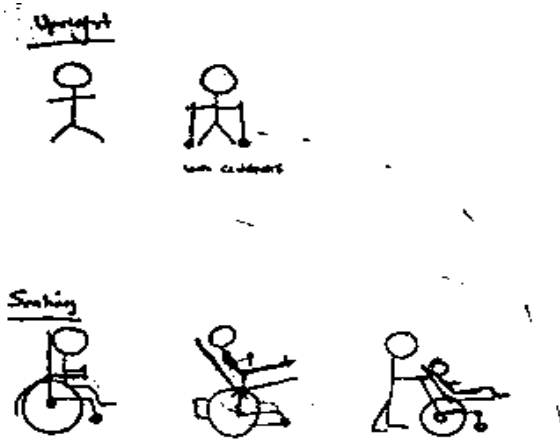


Image 3: Diversity in Bodies of the Children Participants.
Image Courtesy of Lisa Stafford

The six children who used mobility aids habitually revealed that they regard these aids as part of their body (*habitual body*) as is illustrated in the following by P1:³⁹

Interviewer: Ok, so we would use one of these then? [showed wheelchair picture]

P1: No, we walk.

M1: Yeah but you use a wheelchair.

P1: Oh yeah, oh so that's my wheelchair?

Interviewer: Yeah.

M1: You wheel down, you don't walk?

P1: Oh, that's silly.

Through their body experiences, in spaces and time in their lifeworld, it has been revealed that participation to them is a *journey of becoming involved*. The structure of the meaning was understood to involve performing four sequential and interdependent lived movements (i.e. pre-journey, onset, gaining entry, and inside places) to inhabit urban spaces. In reflecting on their experiences, the children revealed that their embodiment of these habitual routines is never straightforward or easy because their corporeality was often made problematic in terms of the spatiality of the situation. These felt differences are highlighted throughout this journey.

A. Pre-Journey

Starting at home, the *pre-journey* lived movement, involves planning and thinking about going out because past encounters of inhabiting and participating in spaces were difficult and at times immobilising. Deciding whether to *avoid* going out or going out by *finding a way* or *picking and choosing* where to go is based on a number of considerations, as illustrated by M5:

Is it going to be suitable when you get there, for not just places in the community but people's home and you know if it doesn't suit you don't get to go, or someone doesn't get to go anyway.

Up to 10 considerations were located in their accounts that needed to be thought through and weighed in order to make decisions, particularly in non-compulsory environments, such as leisure pursuits, social outings, and running errands (see Table 1 for the full list). Many, or most, of these considerations are understood as somewhat interlinked, depending on the spatiality of the situation.

Some conditions, such as time, were themselves complex, multi-dimensional and inter-connected, which also meant they had a significant influence in everyday planning and decision making about going out. From their accounts, four main

Table 1: Conditions Influencing the Decision to go out.

Conditions	
Value of going	Time
Alternatives	Spatial mobility
Past experience	Physical form and layout
Resources	Distance
Conveniences	Climate

dimensions of time were identified. These are timing, regularity, duration, and intensity. *Timing* is defined here in terms of coinciding with other everyday rhythms of life. For example, hospital and therapy appointments always coincided with school and work because they occurred only on weekdays. *Regularity* is defined here as the occurrence of the situation, event, and so on that unfolds in their lifeworld. For example, families spoke of having to battle constantly for resources for their children to attend school. *Intensity* is defined here as the depth and degree involved in achieving something. For example, families with children who embodied wheelchairs reported the complexity and amount of time required to plan a holiday. This became more intense with airplane travel. *Duration* is defined here as the length of experiencing something - generally related to experiencing a

specific activity, setting, or event. For example, children talked about the time to play, or the time to complete a task.

The many meanings of time, and the illustrations of them unfolding in their everyday lives, illustrated how experiences and opportunities are shaped and influenced by, and through, the body-world relations. Time and its meanings revealed here reflect Will Johncock's theorising of time, in this volume, as social, bodily, and participatory.⁴⁰ However, the everyday life of the children and families also make known that sometimes the world, with its rules, attitudes, and conditions, inhibits participatory production of time by smothering opportunity. This makes becoming involved *too hard* or *too difficult* - words commonly expressed by families in this study. Influences of physical-spatial, socio-cultural, and political-legal were also found by Kristy Buccieri to control homeless young people's access to services and basic needs.⁴¹ Time and the other nine conditions reveal the influence they have on leaving the home to go out, as well as the degree of thought and planning families undertake.

B. Onset

If the family has decided to go out, the next part of the journey is the *onset lived movement*, that is the physical act of getting out the door, which involves two body ballets: *leaving the door* and *getting into the car*. The physical act of leaving the door was found to be dependent on others due to their physical needs and having no access to assistive technologies, such as environmental control units, which enable their autonomy to open doors. The novelty of having the freedom to open the door through the use of assistive technology is illustrated by P2/M2:

Interviewer: Like open a door?

M2: Yeah, like "x" does in America. Their whole house has the button... you [P2] sat there all afternoon... thinking it was great that you could open and close doors and run in and out of the house.

Once outside the door the next task is to be loaded into the family vehicle. For children who embodied wheelchairs, their body ballet is revealed as more time-intensive and different depending on the type of vehicle. For example, P1 and P2 each had a family vehicle that accepted their habitual body, but P4, P5, and P7 did not have an accessible family vehicle. In the latter case, the parents described the act of transferring as having to manually lift the child out of their wheelchair and move them into the back seat of the vehicle - an act described as increasingly difficult with their child's growth in age and weight. This is captured by M5: 'Yeah if you don't have a child who can weight bear um you get to a position where it is increasingly difficult to lift them.' From the accounts it was established

that the interaction between the family vehicle and the child's body is a critical point in their journey, having an impact on both the child's and their family's motility.

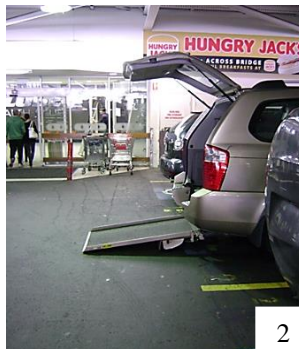
C. Gaining Entry

Once on the journey, the next lived movement performed is *gaining entry* to the intended space. The first body ballet, *finding a car-park*, was not a straightforward act if requiring a wheelchair-accessible car parking bay. Three problems make the act difficult: the design of the car park, number of allocated wheelchair-accessible parks, and parks taken by people without permits. P4 illustrates the felt impact of such an act: '...people just go in the disabled parking 'cause they think normal parking, they just think they can just park there whenever they want.' Using standard parking bays is not an option for six of the children and their families (P1, P2, P4, P5, P7, P8) because the bays are not wide enough to get in and out of the car without difficulty and/or there are concerns for one's safety. When parents of children are unable to find a suitable and safe accessible car-park, the journey to become-involved is commonly discontinued; this means returning home. This is captured by M7: 'And I have been up there and just gone again because getting him out is too hard.'

When the car-park can be navigated, the body ballet of getting out of the car is performed. The changeable conditions and hazards associated with the spatiality of the situation means the act is, at times, felt to be 'dangerous' and 'ridiculous.' This is illustrated in Image 4 and P2's account: 'Like today, like, I had to get out and then turn around and I was in the middle of the road where I was about to get hit.' Image 4 also captures the 'human shields,'⁴² a mitigation strategy used by families in situations where children are emplaced in shared spaces with cars.



1



2



3



Image 4: Performing the Dangerous Ballet in the car park at P2's Regular Hangout.

Images Courtesy of Lisa Stafford

D. Getting Inside

If (or when) the child/family happens to get out of the car, the next body ballet is *getting inside* the spaces, which is felt to be complicated, lengthy, and/or dangerous, due to the multiple hazards. One common account is the *accessible* path of travel is generally a lengthy walk, which is referred to by participants as having to go the *long way around*. The contradiction between the idea of accessible path and the longer distance to travel is further re-informed when children who use a power wheelchair (P1, P2, P4, P7) or walk aided and unaided (P8, P3, P9) report feeling tired and exhausted before getting to the actual intended activity space, because of having to go the *long way*. An illustration of this is capture by P8:

The disabled parking is suppose to be close... It is over there and I can't, by the time I get there it's like, "oh my god this is suppose to be disabled parking." By the time I get there I'm poufed [tired].

In addition to distance, the path of travel from outside to inside is often filled with physical and social barriers to negotiate. Illuminated through the body-time-space rhythms of the children, these problems make-difficult or preclude their participation in these spaces, such as: shopping complexes and home-maker centres, opens spaces like parks and sporting fields, hospitals, and so on. A simple illustration of this is shown from P5/M5's experiences of signs being intentionally placed onto footpaths to prevent pedestrians from using them (refer to Image 5). Whilst almost unfathomable, when one looks further into Image 5, the sense-making of the act emerges. The narrow widths of the paths and the light poles spaced along on the path restricting movement indicate a lack of fore-thought as to

how people will move through, use, and interact within this space; hence the footpaths do not actually permit the use of them as footpaths. What this means is the path of travel to move from the car park to the entry of the space is via the road.



Image 5: P5 / M5's Encounters in Moving through Space: An Afterthought?

Image Courtesy of Lisa Stafford

The lived movement of gaining entry was a critical point in their journey and was revealed to influence the (re)production of differences in their experiences. This is illustrated through the acts and decisions performed by the families, such as the decision to avoid going, to turn around and go home, or to proceed by tolerating discrimination as part of everyday life:

M2: I guess what happens is you just end up getting over the hurdles and you don't see them as hurdles any more. And if something is easy, you're like, "oh my goodness that's easy." It's a bonus.

If (or when) one gets inside, the next act is becoming involved within the space to experience what children described as *fun*, which is understood in their accounts as genuine experiences of *being involved*. Being involved means feeling a deep sense of being part of something and being viewed by others as *normal*. It also means having a sense of choice and making decisions about their involvement. Being involved also means that their bodily needs are appropriately supported and accommodated, and at the same time experiencing joy, risk, and learning from being involved. This description reflects the felt essence of what it means when a child experiences being involved. The significance of this meaning is further made sense of when one grasps the understanding that *being involved* is not their common embodied experience.

Critical to affording genuine experience of being involved is the felt responsiveness of the space. This is true in terms of the needs of the children and their families (focusing in particular on the attitudes and actions of other people and of systems). Four features were located in the time-space-body routines that influence the level of affordance in the particular space being inhabited, these are: the rules, the physical form, resources (such as knowledge, support, equipment/technology, and time), and the actions of others. An illustration where all of these elements meet to afford a genuine participation experience is P7's chance of competing in the school's 400 metre running race, alongside his peers through his habitual way (body + power wheelchair). This experience was afforded through attitudes and actions being responsive to P7's self; this in turn allowed him the opportunity to participate and evoked a sense of *felt-insideness*.

Unfortunately, experiencing genuine participation, like P7, was not frequently encountered in these children's everyday lives. The environment(s) inhabited were rarely responsive to their body-in-the-world, contributing to encounters of partial-involvement or non-involvement. These encounters meant the children were either made to occupy the fringes of the actions - a position considered boring by the children, like P1: 'it's boring watching others' - or they were barred from the environment altogether. P7 expressed a feeling of being alone, and isolated, from his peers and the play environment through his picture communication system (see Image 6). Both positions evoke what Relph describes as a sense of existential outsidership.⁴³

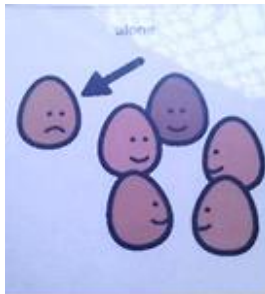


Image 6: Feeling of Being Alone.

Image Courtesy of Mayer-Johnson LLC.⁴⁴

6. Discussion

Why children with diversity in their personal mobility experience such complexity and discrimination in their journey of becoming involved is revealed and understood from the children's own embodied accounts as well as literature of body, space, and disability. To begin with children's bodies, when viewed as

experiencing agents, highlighted the restrictive or enabling environment of their lifeworlds towards their body (that is, their way of being and moving in the world). Where encounters were restrictive, children and their families revealed how their bodily way of being in the world was made to be out-of-place. Children and families felt their placelessness was because of how others, space, and/or systems perceived their body. For example, those with visible physical conditions felt that they were often overlooked because of assumptions about their capacity or safety, whereas those with invisible conditions, such as Juvenile Idiopathic Arthritis, reported being disbelieved as to their felt fatigue and pain in performance. The children's own sense making also suggests that society has a standardised image of the body that occupies the everyday urban life - a body which they feel they do not match.

The upright forward-facing body of adult scale, from which children's bodies were felt to be judged against, are fraught with assumptions. Scholars Dovey and Tuan explain that the uprightness of the body conveys prominence and power in space; a value the body 'only assumes... when he is upright.'⁴⁵ When the body occupies a pose less than standing, the person conveys less power and presence. In space, Dovey describes that the stature of the body is conveyed through the 'dialectic of vertical/horizontal planes';⁴⁶ the vertical plane imparts the body's uprightness. Such perceptions were experienced by the children and their families in this study. They were also revealed to influence the spatiality of situations, which impact on their motility and level of involvement in opportunity, affordance, enjoyment, and/or sense of place. Furthermore, it is these beliefs that many scholars in the disability field feel perpetuates *ableist* norms - a feeling shared by scholars in feminism and childhood studies.

The roots of this narrow view of the body (defining the standard human form, and as such ableist ideology in modern society), has been linked by Imrie to modernism, and conveyed through architecture.⁴⁷ Imrie used the architectural works of Le Corbusier, particularly *The Modulor*, to illustrate how the human body had become reduced to a typical narrow form - an image that continues to pervade urban planning and design today. Imrie also found in architectural practice, that the body itself only comes into the mind of designers to understand and inform 'dimensional requirements' of space;⁴⁸ yet the body informing these dimensional requirements is the upright adult body which lacks 'any differentials in gender, culture, age, and pose.'⁴⁹ The narrow view of how the body is perceived in architecture is a problem from which Keith Peiffer chapter, *Mass Intimacy*, seeks to depart.⁵⁰

Synthesising these findings with the existing knowledge suggests that society conceives of the body, and its expression, in spatial areas of design and planning through forms of inclusion and exclusion. This conceptualisation renders full participation in everyday spaces unattainable for those whose body does not fit standard definitions. Furthermore, the notion of diversity of corporeal form and

children also appears to be taboo - something that needs to be discussed together in the discourses of childhood and disability. Understanding participation through the embodiment of children reveals a critically important step towards the actualisation of diversely mobile children. Examining what it means for these children to achieve full participation in everyday life requires challenging the dichotomy of able/disabled and the homogenisation of *the upright adult body* and *the adult body in situ of a wheelchair*. Neither of these images was revealed by the children to be insufficient in capturing their way of being in the world.

7. Conclusion

The insight provided in this chapter, of children's journey of becoming involved in the urban world, illustrates how their opportunity and experience of *being involved* is particularly influenced by how the child's body and movement, their situation, and the intended space relate. The points of difference encountered by the children, made known through the body ballets, illuminated where felt-experiences are shaped. For example, in the pre-journey, children and their families regularly have to plan and thoroughly think through where to go, what to do, when to try, and what they need to take. They also rely on past experiences as a reference point for making judgments about which spaces to *avoid*, *pick and choose*, *find a way*, and *accept*. At any time in the journey, children and families can be presented with situations described as *difficult*, *ridiculous*, and *dangerous*, that make the children's mobility problematic and continuing the journey too hard.

The embodied accounts also revealed that experiencing a conflicted interplay between body-space-context not only affected the child's potential participation but the whole family unit because *someone always misses out*. To not be defeated, children and families have had to accept that the journey to becoming involved is complex - and never straightforward or easy - because of society's narrow view of the corporeal form, and its way of moving through the world. The embodied routines have provided new understanding in the complex and varied production of participation in the everyday lives of children with diverse mobility and their families.

There are many implications of the findings; one critically important implication is that an understanding of the experience of children with diverse mobility requires us to move beyond discourses of *participation* to the spatial, temporal, and embodied dimensions of everyday urban life. This chapter illustrates that, together, these perspectives allow us to see the role of unnoticed aspects in everyday experience as crucial to urban life. The embodiment of the wheelchair, and the experiences of entering or leaving houses and vehicles stand as examples of these experiences. These insights require three reframes: (i) reframing the body-in-space to reflect the diversity of the corporeal form and movement; (ii) reframing the social group *childhood* to reflect the heterogeneity of this group; and (iii)

reframing participation to reflect both the becoming and being involved that forms the whole experience.

There is so much more to learn about children's participation. However this study has made a contribution to understanding participation as a holistic phenomenon, grounded in the everyday encounters of children with diverse mobility. Furthermore, the findings illustrate the need for the children's participation discourse to move beyond a rights-based framework to everyday life, with the time-space-culture influence shaping both opportunity and experiences. Identifying critical points in the (re)production of differences in experiences - and determining where future interventions in policy, programming, and design can be made - will help to make real and sustainable changes in the lives of these children and their families.

Notes

¹ I wish to acknowledge Barbara Adkins and Jill Franz for their constructive feedback throughout this study. I also wish to acknowledge the non-government organisations' Muscular Dystrophy Association of Queensland, Montrose Access, and Cerebral Palsy League of Queensland for their in-kind support in recruitment, as well as the children and their families who participated in the study.

² UNICEF, *The State of the World's Children 2012: Children in an Urban World* (New York, NY: UNICEF, 2012), World Health Organization, *Global Report on Disability* (Geneva: World Health Organization, 2011), UNICEF, *Promoting the Rights of Children with Disabilities: Innocenti Digest 13* (Italy: UNICEF Innocenti Research Centre, 2007).

³ Kristy Buccieri, this volume.

⁴ Thora Egilson Snaefridur and Rannveig Traustadóttir, 'Theoretical Perspectives and Childhood Participation,' *Scandinavian Journal of Disability Research* 11, no. 1 (2009), 51-63.

⁵ *Ibid.*, 60.

⁶ UNICEF, *The State of the World's Children 2012*, World Health Organization, *Global Report on Disability 2011*; UNICEF, *Promoting the Rights of Children with Disabilities*, 2007.

⁷ Jane Williams and Antonella Invernizzi, eds., *Children and Citizenship* (London, GBR: Sage, 2008), 2.

⁸ Alison James, *Childhood Identities: Self and Social Relationships in the Experience of the Child* (Edinburgh: University Press, 1993), 105.

⁹ *Ibid.*, 105.

- ¹⁰Laura Middleton, *Disabled Children: Challenging Social Exclusion* (Oxford: Blackwell Science, 1999), 121.; Shannon Moore, Luke Melchior, and John Davis, 'Me and the 5 P's: Negotiating Rights-Based Critical Disabilities Studies and Social Inclusion,' *International Journal of Children's Rights* 16, no. 2 (2008): 249-262.
- ¹¹Melinda Jones and Lee Ann Basser-Marks, 'Beyond the Convention on the Rights of the Child: The Rights of Children with Disabilities in International Law,' *The International Journal of Children's Rights* 5, no. 2 (1997): 178.
- ¹²Iris Young, 'Throwing Like a Girl: A Phenomenology of Feminine Body Comportment, Motility and Spatiality,' *Human Studies* 3, no. 2 (1980): 153.
- ¹³Jackie Scully, 'Disability and the Thinking Body,' in *Arguing about Disability: Philosophical Perspectives*, eds. Kristjana Kristiansen, Simo Vehmas, and Tom Shakespeare (Hoboken, NJ: Routledge, 2008), 57-73.; Jan Morris, 'Prejudice,' in *Disabling Barriers: Enabling Environments*, eds. John Swain, Vic Finkelstein, Sally French, and Michael Oliver (London: Sage, 1993), 101-106.; S. Kay Toombs, 'Taking the Body Seriously,' *Hastings Center Report* 27, no. 5 (1997): 42-43.).
- ¹⁴Bill Hughes and Kevin Patterson, 'The Social Model of Disability and the Disappearing Body: Towards Sociology of Impairment,' *Disability & Society* 12, no. 3 (1997): 329.
- ¹⁵*Ibid.*, 329.
- ¹⁶Tom Shakespeare, *Disability Rights and Wrongs* (Oxon: Routledge, 2006), 60.
- ¹⁷See: Kurt Lewin, *Field Theory in Social Science: Selected Theoretical Papers*, 1951. Reprint (Washington, DC: APA, 1997).
- ¹⁸*Ibid.*, 337.
- ¹⁹Joseph de Rivera, *Field Theory as Human-Science: Contributions of Lewin's Berlin Group* (New York, NY: Gardner, 1979), 21.
- ²⁰*Ibid.*, 21.
- ²¹Maurice Merleau-Ponty, *Phenomenology of Perception*, 1945. Reprint, trans. Colin Smith (London: Routledge & Kegan Paul, 1962), 82.
- ²²David Seamon, 'Physical Comminglings: Body, Habit, and Space Transformed into Place,' *Occupation, Participation and Health* 22 (2002): 44s.
- ²³*Ibid.*, 44s.
- ²⁴*Ibid.*, 44s.
- ²⁵Edward Relph, *Place and Placelessness* (London: Pion, 1976).
- ²⁶David Seamon and Jacob Sowers, 'Place and Placelessness (1976): Edward Relph,' in *Key Texts in Human Geography*, eds., Phil Hubbard, Rob Kitchin, and Gill Valentine (London: Sage, 2008), 45.
- ²⁷*Ibid.*, 46.

-
- ²⁸ Richard Lang, 'The Dwelling Door: Towards a Phenomenology of Transition,' in *Dwelling, Place, Environment: Towards a Phenomenology of Person and World*, ed. David Seamon and Robert Mugeraue (New York, NY: Columbia University, 1985), 201-213.
- ²⁹ Howard R. Pollio, Tracy Henley, and Craig B. Thompson, *The Phenomenology of Everyday Life* (New York, NY: Cambridge University Press, 1997), 7.
- ³⁰ Norman Blaikie, *Designing Social Research: The Logic of Anticipation* (Cambridge: Polity, 2000), 15.
- ³¹ Ibid., 115.
- ³² Two specific works were adopted: Max Van Manen, *Researching Lived Experience: Human Science for Action Sensitive Pedagogy* (Albany: State University of New York, 1990), and Karin Dahlberg, Helen Dahlberg, and Maria Nyström, *Reflective Lifeworld Research* (Lund, Sweden: Studentlitteratur AB, 2008).
- ³³ Kathy Charmaz, *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis* (London: Sage, 2006).
- ³⁴ This was referred to as the 'get to know you' meeting with children, as it is less authoritarian than the term 'pre-interview meeting.' The purpose was to obtain formal consent as well as to establish prior knowledge of needs of the children, which Graue & Walsh noted as important. See: Elizabeth Graue and Daniel J. Walsh, *Studying Children in Context: Theories, Methods, and Ethics* (California: Sage, 1998), 92.
- ³⁵ Activity based interviews designed by researcher, Stafford, were: Activity 1 – My Urban Habitat Book, Activity 2 – My Urban Habitat Map; and Activity 3 – My Ideal Urban Habitat.
- ³⁶ Charmaz, *Constructing Grounded Theory*.
- ³⁷ Van Manen, *Researching Lived Experience*; and Dahlberg et al., *Reflective Lifeworld Research*.
- ³⁸ David Cerbone, *Understanding Phenomenology* (Durman, GB: Acumen, 2006), 132.
- ³⁹ All participants are referred to as P1 to P10 to aid anonymity. P2 waved this with the consent in the use of images, however that is only to the people who know him, and hence continues to referred to as P2.
- ⁴⁰ Will Johncock, this volume.
- ⁴¹ Buccieri, this volume.
- ⁴² The human shield is where parent and/or caregiver places his/her body between cars and the children as a mitigation strategy.
- ⁴³ Relph, *Place and Placelessness*.

-
- ⁴⁴ The Picture Communication Symbols ©1981–2011 by Mayer-Johnson LLC. All Rights Reserved Worldwide. Used with permission. Boardmaker® is a trademark of Mayer-Johnson LLC.
 DynaVox Mayer-Johnson
 2100 Wharton Street
 Suite 400
 Pittsburgh, PA 15203
 Phone: 1 (800) 588-4548
 Fax: 1 (866) 585-6260
 Email: mayer-johnson.usa@dynavoxtech.com
 Web site: www.mayer-johnson.com
- ⁴⁵ Yi-Fu Tuan, *Space and Place: The Perspective of Experience* (Minneapolis, MN: University Of Minnesota, 1977), 45.
- ⁴⁶ Kim Dovey, *Framing Power: Mediating Power in Built Form* (Oxon: Routledge, 1999), 49.
- ⁴⁷ Rob Imrie, *Disability and the City: International Perspectives* (New York, NY: Sage Publications Ltd., 1996), 80-89.
- ⁴⁸ Rob Imrie, “‘Architects’ Conception of the Human Body,’ *Environment and Planning D: Society and Space* 21, no. 1 (2003): 47-65.
- ⁴⁹ *Ibid.*, 53.
- ⁴⁹ Keith Peiffer, this volume.

Bibliography

- Blaikie, Norman. *Designing Social Research: The Logic of Anticipation*. Cambridge, MA: Polity, 2000.
- Cerbone, David. *Understanding Phenomenology*. Durman, GB: Acumen, 2006.
- Charmaz, Kathy. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage, 2006.
- Dahlberg, Karin, Helen Dahlberg, and Maria Nyström. *Reflective Lifeworld Research*. Lund, Sweden: Studentlitteratur AB, 2008.
- de Rivera, Joseph. *Field Theory as Human-Science: Contributions of Lewin's Berlin Group*. New York, NY: Gardner, 1979.
- Dovey, Kim. *Framing Power: Mediating Power in Built Form*. Oxon: Routledge, 1999.

Graue, M. Elizabeth and Daniel J. Walsh. *Studying Children in Context: Theories, Methods, and Ethics*. California: Sage, 1998.

Hughes, Bill and Kevin Patterson. 'The Social Model of Disability and the Disappearing Body: Towards Sociology of Impairment.' *Disability & Society* 12, no. 3 (1997): 325-340.

Imrie, Rob. 'Architects' Conception of the Human Body.' *Environment and Planning D: Society and Space* 21, no. 1 (2003): 47-65.

—. *Disability and the City: International Perspectives*. New York, NY: St Martin Press, 1996.

James, Allison. *Childhood Identities: Self and Social Relationships in the Experience of the Child*. Edinburgh: Edinburgh University Press, 1993.

Jones, Melinda and Lee Ann Basser-Marks. 'Beyond the Convention on the Rights of the Child: The Rights of Children with Disabilities in International Law.' *The International Journal of Children's Rights* 5 no. 2 (1997): 177-192.

Lang, Richard. 'The Dwelling Door: Towards a Phenomenology of Transition'. In *Dwelling, Place, Environment: Towards a Phenomenology of Person and World*, edited by David Seamon and Robert Mugeraue, 201-213 New York, NY: Columbia University, 1985.

Lewin, Kurt. *Field Theory in Social Science: Selected Theoretical Papers*. 1951. Reprint. Washington, DC: APA, 1997.

Merleau-Ponty, Maurice. *Phenomenology of Perception*. 1945. Reprint. Translated by Donald A. Landes. London: Routledge, 2012.

Middleton, Laura. *Disabled Children: Challenging Social Exclusion*. Oxford: Blackwell Science, 1999.

Moore, Shannon, Luke Melchior, and John Davis. 'Me and the 5 P's: Negotiating Rights-Based Critical Disabilities Studies and Social Inclusion.' *International Journal of Children's Rights* 16, no. 2 (2008): 249-262.

Morris, Jan. 'Prejudice.' In *Disabling Barriers: Enabling Environments*, edited by John Swain, Vic Finkelstein, Sally French, and Michael Oliver, 101-106. London: Sage, 1993.

Pollio, Howard R., Tracy Henley, and Craig B. Thompson. *The Phenomenology of Everyday Life*. New York, NY: Cambridge University Press, 1997.

Relph, Edward. *Place and Placelessness*. London: Pion, 1976.

Scully, Jackie. 'Disability and the Thinking Body.' In *Arguing about Disability: Philosophical Perspectives*, edited by Kristjana Kristiansen, Simo Vehmas, and Tom Shakespeare, 57-73. Hoboken, NJ: Routledge, 2008.

Seamon, David. 'Physical Comminglings: Body, Habit, and Space Transformed into Place.' *Occupation, Participation and Health* 22 (2002): 42S-51S.

Seamon, David and Jacob Sowers. 'Place and Placelessness (1976): Edward Relph.' In *Key Texts in Human Geography*, edited by Phil Hubbard, Rob Kitchin, and Gill Valentine, 43-52. London: Sage, 2008.

Shakespeare, Tom. *Disability Rights and Wrongs*. Oxon: Routledge, 2006.

Snæfridur, Thora Egilson and Rannveig Traustadóttir. 'Theoretical Perspectives and Childhood Participation.' *Scandinavian Journal of Disability Research* 11, no. 1 (2009): 51-63.

Toombs, Kay. 'Taking the Body Seriously.' *Hastings Center Report* 27, no. 5 (1997): 39-43.

Toombs, Kay. *The Meaning of Illness: A Phenomenological Account of Different Perspectives of Physician and Patient*. Dordrecht: Kluwer, 1993.

Tuan, Yi-Fu. *Space and Place: The Perspective of Experience*. Minneapolis, MN: University Of Minnesota, 1977.

UNICEF. *Promoting the Rights of Children with Disabilities: Innocenti Digest 13*. Italy: UNICEF Innocenti Research Centre, 2007.

UNICEF. *The State of the World's Children 2012: Children in an Urban World*. New York, NY: UNICEF, 2012.

Van Manen, Max. *Researching Lived Experience: Human Science for Action Sensitive Pedagogy*. Albany, NY: State University of New York, 1990.

Williams, Jane and Antonella Invernizzi, eds. *Children and Citizenship*. London: Sage, 2008. World Health Organization. *Global Report on Disability*. Geneva: World Health Organization, 2011.

Young, Iris. 'Throwing Like a Girl: A Phenomenology of Feminine Body Comportment, Motility and Spatiality.' *Human Studies* 3, no. 2 (1980): 137-156.

Lisa Stafford Ph.D. Sessional Academic in the School of Design at the Queensland University of Technology, Brisbane, Australia. While interested in the

person–environment studies from the field of ecological psychology, existential and geographical phenomenology, currently her research and writing is devoted to understanding the phenomenon of *children's participation* as lived by children and young people with diverse abilities through their immersion in spaces comprising urban living.